

DOE/ER/61663--71

**FINAL REPORT ON PLANNING MEETING FOR
INTERNATIONAL YEARBOOK ON
GENETICS, ETHICS, LAW AND SOCIETY (GELS)**

TITLE: Planning for HUGO International Yearbook

PROJECT DIRECTOR: Prof. Alexander Capron

PROJECT TIME PERIOD: 8/15/93-7/31/95

RECIPIENT ORGANIZATION: U.S.C., Los Angeles, CA 90089

DOE AWARD #: DE-FG03-93ER61663

BACKGROUND: The HUGO Ethics Committee consulted with other major international organizations and committees concerned with the ethical, legal, and social issues (ELSI) raised by the genome mapping, and found broad support for two initiatives. The first initiative is to continue and further broaden the dialogue among interested organizations and individuals already begun by the Committee via an International Forum. The second initiative, the subject of this grant, was to build on this exchange of information by utilizing the network of participants in the Forum. The goal of this project is to create an inexpensive and efficient resource of information and analysis in the form of a databank and a published compilation, the HUGO INTERNATIONAL YEARBOOK: GELS. The GELS YEARBOOK would enable people in science, medicine, government, law, and ethics around the world to stay abreast of statutes, regulations, guidelines, and analysis produced by their counterparts in other nations and international organizations.

PURPOSE: The purpose of the project was to convene a meeting of a planning committee, consisting primarily of internationally representative ELSI experts as well as several specialists in bibliographic and documentation methodologies, and to take other steps in a planning process which would flesh out the details of GELS at both structural and intellectual levels. The use of an expert committee was intended to aid the principal investigators in identifying the means of gathering GELS information, establishing the structure of the data bank, determining analytic categories and recruiting experts capable of performing analysis and synthesis on a topical as well as a geographic basis, and determining how the GELS YEARBOOK will be published and what methods will be used to allow access to the databank between annual issues. The result of the planning process would be a proposal on how to fill the gap produced by the lack of exchange of information and action on ethical, legal, and social issues in genetics throughout the world. [In addition to the support provided the American Principal Investigator (A. M. Capron) under the DOE grant, the project also benefited from support provided to the Canadian Principal Investigator (Bartha M. Knoppers) under a CGAT (Canadian Genome and Technology) grant.]

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RESULTS: On December 17-18, 1993, an international group of ethics and genetics experts, as well as specialists in several important areas, and representatives of HUGO and of the U.S. ELSI programs met with professors Capron and Knoppers in Washington, DC. This Advisory Committee consisted of Ruth Chadwick (UK) of the University of Central Lancashire, Hernan Fuenzalida (Latin America) of the World Health Organization, Segun Gbadegesun (Africa) of Howard University, Ruito Kimura (Asia) of Georgetown University, Francoise Touraine-Moulin (Europe) of BP Lyon Montchat, Nancy Wexler (U.S.) of Columbia University, Sev S. Fluss (Europe) of the World Health Organization, Maurice A.M. de Wachter (Europe) of Maastricht Bioethics Institute, Leroy Walters (bibliographic methods) of Georgetown University, Michael Yesley (bibliographic methods) of the Department of Energy, David T. Kingsbury (electronic data management) of Johns Hopkins University, Diane Isonaka (HUGO) of the Darwin Molecular Corporation, Eric T. Juengst (ELSI) of the National Institutes of Health, and Daniel W. Drell (ELSI) of the Department of Energy. The GELS advisory committee suggested that an International Yearbook strengthen regional/ international cooperation and collaboration between already existing associations and groups concerned with GELS issues. The Committee also suggested that the Yearbook standardize terminology in a timely and efficient manner and publish in a limited number of languages (English; French; Spanish) and be sensitive to differing cultural contexts, needs and priorities. In order to achieve these objectives, the following methodology was discussed: preparation of an index of terms/ subject matter or use of the existing Kennedy Institute Index; creation of multiple modes of access and multiple modes of distribution (paper, on-line, bulletin boards, E-mail, other multimedia possibilities), conservation of all contributions in their original language (repository), and participation with existing international governmental and non-governmental organizations (together with HUGO) to establish international legitimacy and international dissemination. In sum, when operational, the project should fulfill four functions: accumulation of GELS information; organization of GELS databank/ repository; examination of GELS issues; and dissemination of GELS in on-line and printed forms.

CURRENT STATUS OF GELS: GELS will have two principal components, an electronic DATABANK and a loose-leaf REPORTER. The Databank will be freely accessible on the World Wide Web (WWW) through file-servers at USC (in English) and at Montreal (in French). It will contain several types of materials. First, documents written in Roman letters will be entered and will be searchable and down-loadable. Documents in non-Roman text will be scanned and accessible in graphic format. Second, an abstract will be prepared for each document to aid in browsing. Third, the analyses of regional/ international trends and of topical developments prepared for GELS will be available three months after they are distributed in printed form in the GELS Reporter. Finally, the bibliography on ethical and legal issues in genome mapping and genetics prepared by Michael Yesley of the Department of Energy will be linked to the GELS databank. The GELS Reporter will appear twice each year as loose-leaf pages to be added to a tabbed set of binders. Each distribution will contain expert analysis of several important topics. Each distribution will also describe notable recent developments in particular geographic regions and among international organizations. In sum, using the Databank and the Reporter, scholars, officials and other interested parties will have access to virtually all legal, regulatory, and ethical materials from governments, non-governmental organizations, and major professional bodies concerning the development and use of genome maps and genetic data organized on a topical and geographical basis.